THE CAREGIVER'S HANDBOOK

A helping hand for families and friends giving care in Nova Scotia

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L'Université canadienne
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Le Centre d'excellence de l'Atlantique pour la santé des femmes
Atlantic Centre of Excellence for Women's Health

Nova Scotia Advisory Council on the Status of Women
Conseil consultatif sur la condition féminine de la Nouvelle-Écosse

CIHR IRSC
Canadian Institutes of Health Research

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A helping hand for friends and family giving care in Nova Scotia

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The information provided in this handbook is intended for broad consumer understanding of information related to caregiving. This information should not be considered complete and should not be used in the place of advice or consultation with a trained professional. If you have a health-related problem, we strongly suggest that you visit your health care provider, or in the event of an emergency, contact your local emergency department.

The information contained in this handbook should not be construed to be formal legal or medical advice, nor the formation of a client relationship. This information has been compiled from a variety of sources. The Healthy Balance Research Program or its directors shall not be responsible for information provided here, under any theory of liability or indemnity.

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We would like to dedicate this resource to all the unpaid caregivers in Nova Scotia and across Canada who give their time and support to others.

Welcome to the Caregiver's Handbook!

The Healthy Balance Research Program was launched more than five years ago when we began discussing the need to know more about caregiving in Nova Scotia. We knew that there were many people in communities across the province caring for children, spouses, parents, and others, but we did not know how many Nova Scotians were providing care, what type of care they were providing or what impact their caregiving role might have on their health, relationships and financial well-being.

We brought together researchers to examine these questions. We also brought together Equity Reference Groups including immigrant women, African Nova Scotian women, women with disabilities, and Aboriginal women. The members of the Equity Reference Groups have played an important role in the Healthy Balance Research Program. They have helped the researchers make sure that their work will be useful to the many people providing unpaid care in Nova Scotia. The Caregiver's Handbook is a direct result of our conversations with the Equity Reference Groups' members.

Many caregivers who took part in this work talked about how difficult it was to find programs, services, and information about caregiving. They have told us that they sometimes feel alone and unsure of what choices are available.

Caregivers feel this role is immensely rewarding. It is also challenging and demanding. We hope this handbook will enhance the rewards by helping you deal with some of the challenges and the demands. The handbook is full of tools, tips, and resources intended to help and support you in this role.

If you are not a caregiver, we hope that this handbook will give you something to think about. What kind of care would you like if you yourself became ill, frail or disabled? Who would provide that care? Where would you live? What would you do if someone close to you needed care? Do you want to be a caregiver? How might caregiving affect your life? How can you support a caregiver that you know?

We hope that the Caregiver's Handbook helps you to think about the care you may both need and provide, now or in the future, and the ways in which caring makes our communities stronger.

About this book...

As you read the Caregiver's Handbook, you will notice quotations in red boxes like this one throughout the book. These quotations are from caregivers like yourself who live in Nova Scotia and care for friends or family members.You can find more information about these caregivers in the resource "Snapshots of the Lives of Caregivers: 'I Do It Because I Love Her and I Care' (see page 73). They are all caregivers who were involved in the research of the Healthy Balance Research Program.

In some parts of the book, we have referred to information from the Healthy Balance research, or from other publications. When you see a number at the end of a sentence, it means that the information in that sentence is from the publication with that number in the list at the back of this book.

Please note that the Caregiver's Handbook is also available in French.

Acknowledgements

The Healthy Balance Research Program would like to extend thanks to the Canadian Institutes of Health Research for funding this five-year program of research on caregiving in Nova Scotia. The program has also been supported by Dalhousie University, the IWK Health Centre and Health Canada's Bureau of Women's Health and Gender Analysis.

In addition, we would like to thank the organizations whose specific funding and in-kind contributions have made the publication of this handbook possible: Nova Scotia Department of Health Promotion and Protection, Nova Scotia Seniors' Secretariat, Human Resources and Social Development Canada, and the Nova Scotia Office of Acadian Affairs.

There have been many people involved in the production of this handbook and their contributions have been vital to its success.

We would like to thank the Equity Reference Groups' members for their dedication to the research program and for inspiring the Caregiver's Handbook as a resource.

We would like to thank the Caregiver Resource Working Group for their guidance, expertise and feedback throughout the production of the handbook. The Working Group included representatives from the Nova Scotia Advisory Council on the Status of Women, Caregivers Nova Scotia, Nova Scotia Seniors' Secretariat, Nova Scotia Department of Health Promotion and Protection, and Nova Scotia Department of Health.

We would like to thank the community reviewers for volunteering their time to ensure that the handbook is as useful for caregivers as possible: Fiona, Glenda, Susan, Maria, Dianne, Evie, Patricia, Doreen, Denise, Marcie, Tami, Jean, Louise, and Marlene.

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Special Thanks to Caregivers Nova Scotia

This first edition of the Caregiver's Handbook has been produced by the Healthy Balance Research Program with the help of many contributors. In particular, the Healthy Balance Research Program would like to extend thanks to Caregivers Nova Scotia for their expertise and support.

We are also pleased that Caregivers Nova Scotia intends to produce future editions of the Caregiver's Handbook. As with any printed publication, some information may become out of date or new information may become available. Caregivers Nova Scotia would appreciate your assistance in keeping future editions as up to date and comprehensive as possible. If you have suggestions for the next edition of the Caregiver's Handbook, please contact:

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Caregivers Nova Scotia is a non-profit organization dedicated to providing recognition and practical supports to friends and family giving care. Their vision is: "Caregivers are supported as essential partners in care."

Their services for caregivers take many forms, including workshops, informative newsletters focused on caregiving issues, a book and video lending library, telephone caregiver assistance, and community-based peer support groups. In addition, they participate in various government Task Forces and Working Groups to help influence public policy for the benefit of caregivers.

Caregivers in Nova Scotia

There are many different kinds of caregivers: health care professionals are care providers to their patients; people who volunteer with community organizations can be caregivers; parents are caregivers to their children; and thousands of others are caregivers to their families or friends when extra help is needed. This handbook was designed especially for this last group – family and friends giving care in Nova Scotia.

In this book, the term "caregiver" refers to someone who cares for a person who is ill, who has a disability, or who is restricted in some way by their health. Examples of caregivers include adult children who look after parents with a chronic disease, mothers who care for children with disabilities, teenagers who help parents after a stroke, and friends or neighbours who take someone to medical appointments or help with household chores.

Who is a caregiver?

In 2005, about 36% of Nova Scotians – roughly 250,000 people in this province – provided some form of unpaid care to another person.[1]

Caregivers live in both rural and urban areas. Caregivers include people of diverse racial, cultural and linguistic backgrounds, different sexual orientations, and persons with disabilities. Many people of all backgrounds and walks of life are involved in caregiving.

Caregivers include both men and women, though women are more likely than men to be caring for a friend or family member. Women are also more likely to take on intense and long-term caregiving involving personal care on a daily basis.

Who do caregivers care for?

In short, everyone. Caregivers in Nova Scotia give care to immediate and extended family members, friends, neighbours, co-workers, and others in their communities. Although most caregivers care for an elderly person, many care for children or dependent adults. Some care for more than one person, and some people receive care from more than one caregiver. Caregivers may care for someone who lives with them, but most care for someone who lives in a place of their own.[1]

What do caregivers do?

Every caregiving situation is different, but most caregivers in Nova Scotia are helping out in at least one of the following areas:

- Personal Care: bathing, dressing, lifting/transferring, administering medications
- Help Around the House: housecleaning, laundry, meal preparation, yard/outdoor work
- Transportation and Shopping: accompanying care receiver to appointments, shopping
- Orchestrating Care: finding out about available services, arranging appointments and services, negotiating and advocating for the care receiver
- Psycho-social Support: checking in, visiting
- Financial and Legal Affairs: banking, taking care of legal documents, income taxes.[1]

Caregivers are vital to the lives of the people they care for, and caregivers contribute to society in many other ways.

Financially, caregivers in Canada are estimated to save the health system more than $5 billion a year.[19] Today, with an aging population and fewer people to provide care, the importance of unpaid caregivers is becoming even more critical. In their communities, caregivers do many things in addition to the care they provide. Many are raising children, serving as volunteers, working in paid employment – or all three.

In other words, caregivers are a vital part of our society. By supporting them, we can all contribute to stronger and healthier communities.

When your Caregiving Journey Begins....

Many Nova Scotians become caregivers overnight when a friend or family member becomes ill or is injured. Others take on more and more caregiving tasks gradually as a care receiver's health declines or when other caregivers need a break. Regardless of how it happens, when a need for caregiving arises, there are many things to think about.

Do you want to be a caregiver?

For some of us, there is no time to think about this question. Many people feel that they don't have other options and some feel obliged to provide care. Women may feel particularly pressured to take on caregiving roles because of assumptions that women are caring and nurturing.

> **And she said "Can I live with you?" And I said yes. Even though that wasn't what I was prepared for and I didn't think that's what was going to happen... I think she asked me because deep down she knew I would say yes and not stand by and see her go into a hospital or nursing home.**

It is important, however, to recognize and respect that every individual should have the right to choose to provide care or not. Taking on the role of caregiver will affect all aspects of your life – some positively and some negatively.

Exercise: Considering the effects of caregiving

Take a moment to ask yourself how caregiving might affect:

1. My relationship with the person receiving care?

2. My relationship(s) with my partner, my children, my parents, my other family members, and my friends?

3. My social life, recreation and friendships?

4. My health?

5. My career and my job?

6. My finances?

7. My future?

What role will you play?

The caregiving experience is different for everyone. It's important to understand what being a caregiver will mean for you, what you want to do and what you are able to do. It is worthwhile to set boundaries and clarify expectations at the beginning of your caregiving journey if possible, as it can be much harder to do when you're already deeply involved and committed. These questions will help you define your own role.

- Do I want to be the primary caregiver? How much care do I want to provide? How involved would I like to be in decisions about care? What does the care receiver want and need?

- What type of care will I provide? What are my skills and resources? What types of tasks am I comfortable with and able to do? What types of tasks am I not comfortable with or unable to do?

- Are there other people who can provide care, give me a break, and support me in my work? Who are they, and how can they help?

- How will I feel about myself if I choose to be a caregiver? How will I feel about myself if I choose not to be a caregiver?

Communicating with friends and family

Providing care to another person is both challenging and rewarding. Now that you have thought about your role as a caregiver, it will be helpful to discuss your ideas and your feelings with family, friends and others. Whether you have recently become a caregiver or have been providing care for many years, it is important that those around you understand what caregiving means to you.

> **I feel I work as hard as the next one or I work as long as the next one, absolutely. And don't get anything for it.**

Whether you bring your family together for coffee, chat with friends over the phone, or organize a meeting of everyone who is helping you provide care, it is important to share your thoughts. This may help others see how they can contribute to the care and support you.

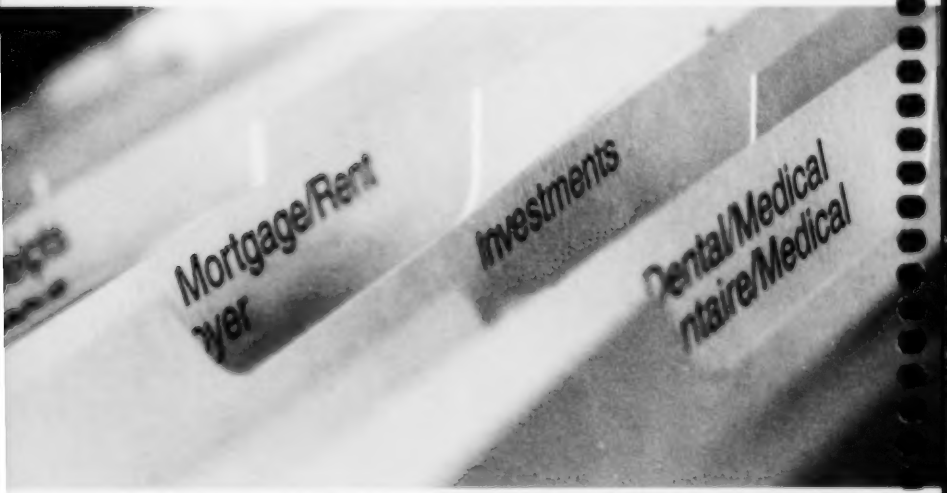
> **I love her, and you know we can have fun together. I really like helping her, I like making her life better, I like to make her happy, I get joy out of giving her joy... So I do it because I love her and I care. Both because she's my mother and I'm a person who cares, just cares about her.**

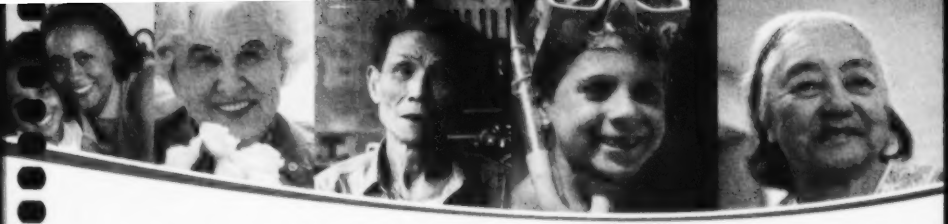
Getting Organized

Most caregivers are trying to balance their caregiving with other responsibilities. You've probably heard about the importance of taking time for yourself, and you've probably wondered how on earth to make that happen!

> **...so I ended up doing the cooking, the cleaning, maintaining the finances, doing taxes, the driving, buying the groceries, cooking the meals, doing the yard work, cleaning the basement, doing the mowing of the lawn... plus going to school, I mean at that time I was in high school.**

In this section, you will find checklists, forms and charts – all tools that we hope will help you to get organized and find some time for yourself.





Developing a Daily Care Plan

Step 1 – Assess your needs and take an inventory of your skills and the resources available to you.

What are your needs? Are there things that others could do to help you in your role as caregiver or to give you a break from caregiving?

Activities	Who can help?	When/How often?
Personal Care		
Bathing		
Dressing		
Lifting		
Medications		

Activities	Who can help?	When/How often?
Help Around the House		
Housecleaning		
Laundry		
Meal preparation		
Yard/outdoor work		
Care for pets, plants		
Check mail		
Transportation/Shopping		
Accompany to appointments		
Take shopping (groceries or other)		
Fill prescriptions		
Car maintenance		

Activities	Who can help?	When/How often?
Orchestrating Care		
Research available services		
Arrange appointments		
Psycho-social Support		
Check-in, visit		
Financial/Legal Affairs		
Banking, pay bills		
Legal documents		
Income taxes		

Notes:

Step 2 – Once you have developed a list of your needs, skills and resources, you can create a daily care plan – a schedule to keep track of things that need to be done and who can help throughout the week.

Daily Care Plan

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Sunday

Medications

If keeping track of medications is one of your caregiving tasks, a medication chart can help. It can serve as a record of all medications taken and as a reminder to take medications on schedule. It is particularly useful for respite workers or other friends and family who may help to support the caregiver.

A few tips:

- Keep the record up to date with both prescription and non-prescription medications.
- Take the record to all doctors' appointments and to the pharmacy each time you pick up a prescription.
- Use the same pharmacy for all prescriptions. This will help the pharmacist to identify potential drug interactions.
- Use the Vial of Life to keep important medication information in your refrigerator (see page 64 for details)

MEDICATION CHART for:

Name of medication	What does it look like?	What is it for?	How much to give and when?	Special Instructions	Side Effects	Prescribed by/ Available at
EXAMPLE Tylenol	White Tablet with a 'T'	Pain	2 pills every 8 hours	Take with food	None	Dr. Smith ABC Pharmacy

ALLERGIES:

IMMUNIZATION RECORD: Record the year of the last immunization.

Tetanus: _____ Flu Shot: _____ Pneumonia: _____ Hepatitis: _____ Other: _____

Meal planning

Deciding what to cook for supper is a daily hassle for most people. For caregivers, it can be even more stressful when combined with other responsibilities. There are so many things to think about... Is it healthy? Does anyone have allergies or other dietary restrictions? Do I have the ingredients? How much time do I have? Will there be leftovers?

You may find it helpful to plan meals for a week or more at a time. Here are a few tips to get you started:

1. **Collect recipes that work for you.**

   Look for meals that:
   - use ingredients that are easy to find;
   - are affordable;
   - can be prepared quickly; and
   - are healthy.

Healthy Cooking Tips
(from Canada's Food Guide)

- Cook with oils that are low in saturated fats (olive, canola, and soybean oil).
- Choose dark green and orange vegetables as often as possible (broccoli, romaine lettuce, carrots, and sweet potatoes, for example).
- Choose whole grain bread, oatmeal or whole wheat pasta.
- Eat at least two servings of fish each week.
- Read the 'Nutrition Facts' labels and look for foods that have less fat, sugar and sodium.

2. **Fill in the meal planning guide on the next page.**
3. **Make a grocery list based on the recipes you have chosen for the week.**

MEAL PLANNING

Allergies/Dietary Restrictions:

Preferences:

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Breakfast							
Snack							
Lunch							
Snack							
Supper							

The "To Do" List

Have you ever had a friend or family member ask, "How can I help?" Sometimes people would like to help with caregiving, but aren't sure what they should do. If you have some ideas ahead of time, you can be prepared to take them up on their offer to help.

It may help to sit down and write a list of all the things that you regularly do (or want to do) in a week. Include everything: your employment, your housework, caring for children or other family members, caregiving tasks, time for yourself, shopping, and exercising, to name a few things. Once you have a complete list, look over it and see if there are things that you could spend less time on, things that a friend, neighbour or family member could do for you, or things that a home care or respite worker might be able to help you with. Write all of the things that others could help out with on a separate list, and keep it on the fridge or in a visible place where people who want to help will see what needs to be done. Below are a few examples of things that might be on your "to do" list that others could help out with. A blank list for you to fill out is on the following page.

Sample "To Do" List:

Frequent tasks:

- Laundry
- Sweeping/vacuuming/dusting
- Yard work/snow shovelling
- Shopping for groceries
- Cooking and cleaning up after meals
- Visit with caregiver and/or care receiver
- Go with care receiver to appointments
- Look into resources or services that may be needed

Occasional tasks:

- Take the car in for an oil change/maintenance
- Arrange for home maintenance (plumbing, heating and electrical work)
- Pay bills and taxes

The "To Do" List

Frequent tasks:

Occasional tasks:

Taking Care of Yourself

I do take walks, I just have to. I need to get out, just for relief... I love them.

Caregiving can be very rewarding, but it is also hard work. Finding time for yourself and staying healthy are essential, but like most caregivers, you're probably wondering just where you'll find that time!

What does it mean to be healthy?

Health has been defined in many different ways at different times and by different groups. Today health is broadly defined and includes physical, mental, social, and spiritual well-being.

The demands of caregiving can negatively affect health and well-being. Caregivers reported that their caregiving led to negative stress, feelings of depression and helplessness, physical injury, high blood pressure, poor eating habits, and disturbed sleep.[4] More time spent on caregiving means less time for leisure and social activities[4], and can result in lost friendships and family conflict.

What does 'being healthy' mean to you...

Physically?

Mentally?

Socially?

Spiritually?

Do you feel healthy? What things in your life help to improve your health? What things in your life affect your health negatively?

For many people, including caregivers, the most challenging thing about achieving and maintaining good health is finding balance.

> **I feel like I'm a teacher, I'm a daughter, I'm wife, I'm psychologist... I'm everything.**

Here are a few tips that might help you find a healthy balance.

Coping with stress

Everyone is stressed from time to time, but long or intense periods of stress can be extremely hard on your health, both physical and mental. The Canadian Mental Health Association recommends that everyone take some time to: assess the level and causes of their stress, talk about it, reduce tension, and prevent future stress.

Step 1: Check-in on your stress level

This quiz may help you to reflect on how you're feeling and to think about the level of stress in your life.*

	Never	Sometimes	Usually	Almost Always
I cannot get enough sleep.	0	1	2	3
I have conflicts with my friends or family members.	0	1	2	3
I feel anxious.	0	1	2	3
I feel like I have no time for myself.	0	1	2	3
I worry that I am not doing a good job as a caregiver.	0	1	2	3
I feel depressed, trapped, or resentful.	0	1	2	3

Your Score:

0 - 7 You are managing well. Remember that it's still important to think about ways of preventing stress from building up.

8 - 12 You may need to seek out some additional support. Try to identify the things that are causing you stress – you may not be able to change all of them, but there may be areas where you can ask for help or make changes to relieve some of your stress.

13 + You may be experiencing caregiver burnout. It's important that you talk to friends, family, a support group, or your family doctor about your stress.

This test can help you to reflect on the stresses in your life and how you are managing them. Check back on this quiz from time to time to see how you're doing. If you are having a hard time coping with stress, consider talking to your doctor.

*This quiz was adapted from:
http://www.silverselect.com/resource_center/Caregiver%20Stress%20Quiz.pdf

Step 2: Figure out what causes you stress

Stressors can range from major life events like changing jobs or the death of a loved one to long-term worries about your finances or health to daily hassles like traffic jams or household chores. It may help you to think of the things in your own life that are contributing to your stress level. Here is a list of things that commonly cause stress, with space for you to write about the stressors in your life.

- Loss of a partner, family member, or friend
- Changes in your health: injury, illness, pregnancy
- Drug abuse, alcoholism, self-harm
- Changes in your family: separation, divorce, new baby, marriage
- Changes in sexual activity: a new partner, lack of desire, sexual health concerns
- Personal conflict: with a partner, family members, friends, co-workers, boss, health care providers
- Physical changes: lack of sleep, new work hours
- A major purchase: vacation, new car, new house
- Financial concerns: making ends meet, paying debts, planning for the future
- Change in environment: new school, job, town/city
- Increase in responsibility: caregiving, inheritance

Step 3: Talk about it.

Find someone to talk with about your feelings.

Friends and family members are often the first people to turn to for support. If there is someone in your life who you think would be supportive, start by calling them or inviting them over for a visit.

Support groups can help you relieve stress, find resources, and reduce feelings of isolation by sharing experiences and information with others. To find an active support group in your area, contact Caregivers Nova Scotia toll-free at 1-877-488-7390 or in Halifax at (902) 421-7390.

Your family doctor is another person who may be able to help. Tell the doctor about your feelings and ask for advice. You may be referred to a counsellor or psychologist.

Your spiritual advisor may also be able to provide counselling, guidance or advice during times of need.

Step 4: Reduce tension.

Physical activity is a great way to reduce stress. Go for a walk, take up a sport, dig in the garden, or take a few minutes to do some simple stretches.

Guided relaxation exercises may help you cope with stress and they offer a good reason to take a few minutes for yourself each day. Try the exercise on the following page. If you want to learn more about guided relaxation, try looking on the Internet where you will find information and audio files on many websites such as www.relaxation.com. Your local library or bookstore will likely offer a variety of books and audio recordings on the subject.

Guided Relaxation Exercise

If possible, set aside 15 minutes each day when you are not likely to be interrupted to do this guided relaxation exercise.

Find a place where you feel most comfortable, whether it's your bedroom, your favourite chair, or the backyard. Sit comfortably or lay down on your back with your arms resting at your side.

Take a deep breath and exhale slowly. Breathe in through your nose for a slow count of seven, hold your breath for a moment, and breathe out through your mouth for a slow count of seven. Repeat this several times as you focus only on your breath as it fills your lungs and expands your chest. If you like, exhale with a sigh.

Each breath flows seamlessly in through your nose and out through your mouth. Focus on the parts of your body where you hold tension. As you inhale, imagine that your breath moves to that area of tension. As you exhale, the tension flows out of your body with your breath. Repeat this for each of the tense areas of your body.

Now focus your attention on your toes. As you inhale, your breath reaches all the way down to your toes. Tense your toes while you hold your breath for a few seconds, and as you exhale allow the tension in your toes to melt away. Next, breathe in to your ankles and calves. Tense up your lower legs as you hold your breath for a few seconds, and release the tension as you exhale slowly.

Breathe deeply and focus your attention on your knees. Squeeze the muscles around your knees and relax as you exhale. Continue to move up your body, taking a deep breath, tensing each area, and releasing the tension as you exhale. Your thighs, your pelvis, your abdomen, your lower back, your rib cage, your chest, your shoulders, arms, and hands, your neck, your ears, and your face… Breathe in slowly through your nose, and exhale through your mouth as you release the tension in your body.

Take a moment to scan your body. Are there any areas that still seem tense? Repeat the tense and relax exercise a few times for those areas.

Take a few more minutes to breathe in through your nose for a slow count of seven, hold your breath, and breathe out through your mouth for a slow count of seven.

Once you are familiar with this exercise, you may find it helpful to close your eyes as you enjoy this guided relaxation.

Step 5: Prevent stress

Keep up with the above activities even when you're feeling less stressed. This will help to prevent stress from building up again. A few other things you can do to prevent stress are:

Make decisions – not making decisions causes worry and stress.

Avoid putting things off – make a weekly schedule that includes leisure activities and time for yourself whenever possible.

Delegate – get others to do tasks so that you are not trying to do everything by yourself.

For more information on coping with stress or other aspects of your mental health, contact:

The Canadian Mental Health Association
Phone: (416) 484-7750
Web: **www.cmha.ca**

Acknowledging your feelings

Guilt, anger, frustration, and grief are all emotions that caregivers may experience, especially if there have been recent changes with the care receiver, at work, with money, in the home, or in other aspects of their lives.

It's important to acknowledge your feelings and remember that you're not alone. Keep in mind that more than one-third of Nova Scotians are caregivers, and many of them have the same feelings you do. Try to express your anger in helpful ways, grieve when you need to, and celebrate the happy moments, too.

If negative feelings become overwhelming, or you feel depressed or anxious, talk to your doctor.

Striving for balance (not perfection)

You have to know yourself, how much stamina you have.

Try to set **realistic goals**. Know your limits and say "no" to taking on more than you can handle.

If you do find yourself with too much to do, **ask for help**. Accepting or asking for help is an important skill and it's not always easy. Here are a few tips.

Where to turn...

You never know where you'll find help when you need it. Start by browsing through this book. The sections entitled "Services in Nova Scotia" and "Information and Support" might give you some ideas. Turn to family members, friends, neighbours, a local community group, or church. Some employers may also offer employee assistance programs that could be helpful.

How to ask...

Ask for help with specific tasks – use the "To Do" List discussed earlier (see page 18) to give people suggestions about what they can do to support you. Many people are eager to help but not sure what they can do.

It may take time to feel comfortable asking for help, but it will likely get easier as you do it more often.

Taking time for yourself

Although this is easier said than done, it is also very important. Even a 15-minute break can help you feel refreshed and energized.

In the short term, you might build small breaks into your daily plan. Fifteen minutes for reading or doing a crossword puzzle, or half an hour for a walk or a relaxing bath are great ways to take a well-deserved break.

In the long term, everyone needs a longer rest period. If possible, take advantage of respite care, which may offer a few hours of in-home support or provide several days or weeks of care so that you can take a vacation (see page 57 for more information). Ask close friends and family members to stay with your care receiver and give you a break. Try to use the time to do something for yourself instead of running more errands. Visit with a friend, join a fitness class, or start a new hobby.

Eating healthy, exercising and sleep

Canada's Guide to Healthy Eating and Physical Activity recommends the following:

Healthy Eating

We know that health is improved by:

- enjoying foods from each of the four food groups;
- eating foods mainly from the "Grain Products," "Vegetables," and "Fruit" groups;

- drinking skim, partly skim, or reduced-fat milk;
- baking, broiling or microwaving food instead of frying it;
- eating more peas, beans and lentils; and
- snacking on chips and chocolate less often.

Physical Activity

You can also improve your health by:

- getting 30-60 minutes of moderate physical activity each day. This includes things like gardening, housework, and walking.
- choosing a variety of activities from these groups:
  - for your heart, lungs and circulatory system (biking, swimming, dancing, brisk walking)
  - to keep your muscles relaxed and your joints mobile (Yoga, Tai Chi, simple stretches)
  - to strengthen muscles and bones and improve posture (Pilates, lifting small weights).

  This doesn't mean you need to work out at the gym for an hour each day. You can build your physical activity through the day in periods of at least 10 minutes each. As a caregiver, some of the activities you do are likely physically demanding. Yard work, household chores, walking to the grocery store, and heavy lifting (such as moving your care receiver) all contribute to your daily physical activity. However, since these activities may be stressful, try to balance them with less stressful activities that will also give you a break from your caregiving.

... I couldn't fit my exercise in. And that was bothering me... That was stressing me out a little bit, not being able to do that. You know, it's something I like to do.

Sleep

Most people do not get eight hours of sleep each night, and caregivers in Nova Scotia have said that they often have a disturbed sleep. Sleep is very important; it allows your body to restore itself and prepare for the next day. When you don't get enough sleep, you might be edgy, less able to deal with stressful situations, and more prone to illness. The Canadian Health Network recommends that you:

- develop a regular routine; go to bed and wake up at around the same time each day;
- avoid smoking and caffeine;
- have a relaxing bath or read a book before bed; and
- avoid strenuous activity close to bedtime.

When Things Change

As a caregiver, your role is always changing. Sometimes changes happen gradually as a care receiver becomes healthier and no longer requires care, or as an illness progresses and becomes more serious. Other times, changes can happen abruptly when a care receiver passes away. In any of these times of transition, changes to your role as a caregiver can be challenging.

Like any major transition in your life, changes will likely involve mixed emotions – grief, anger, sadness, confusion, and relief are just a few examples.

Grieving

Grief is commonly experienced by caregivers during times of transition. It can refer to the sadness felt when a loved one passes away, but it can also occur when your responsibilities change, such as if your care receiver moves into a long-term care facility. It is also common to grieve if your relationship with your care receiver changes – whether it changes because of a divorce or separation, or because your care receiver's memory or personality changes with Alzheimer's disease or other forms of dementia. Grieving can also begin long before a person passes away, which is often referred to as 'anticipatory grief.'

> **It was like... this is it for Mum, this is it; she is going to die here. I mean... I've been grieving her, and grieving her, and grieving her this year, like every time I go see her I come back and I'm grieving some more. A lot of grieving. I miss her.**

The important thing to remember is that grief and other emotions are normal. Give yourself permission to grieve, to laugh, to be angry, and to cry. You may need extra support from family and friends during these times. You may also want to seek support from your doctor, a counsellor, your local church, or a support group. To find an active peer support group in your area, contact Caregivers Nova Scotia toll-free at 1-877-488-7390 or in Halifax at (902) 421-7390.

Moving Forward

In addition to the emotions that you experience, there will be a lot of things to think about and many questions to answer. You may be thinking about some major changes in your life – going back to paid employment, moving into another home, starting a family, or perhaps you are ready for retirement. This may be a good time to reflect on your experience of caregiving.

Have you developed new skills since you became a caregiver? What are they? How do these skills enhance your personal life or your career?

Do you have different interests now than you did before you became a caregiver? How have things changed?

What things have you learned about yourself?

What have you learned about friends, family members, neighbours, or others?

Being an Advocate

Caregivers are advocates. If you have ever requested a service for your care receiver, taken time to educate others about caregiving, or talked to a local politician about issues related to caregiving, then you have been an advocate.

> **You'll disappoint yourself in this role and you'll surprise yourself in this role, at the strength that you have sometimes.**

Advocating for your care receiver and yourself

You will likely find yourself advocating for your care receiver on many occasions. You may need to become familiar with a health insurance policy, request a suitable housing option, or suggest changes to improve existing services.

Don't forget to advocate for yourself! As a caregiver, you also deserve to have the support that you need, and service providers need to hear from you so that they can better meet your needs, and the needs of other caregivers.

Not everyone feels comfortable in an advocacy role. Sometimes the best thing you can do to advocate for yourself and for others is to ask for help. If you know someone who has a knack for speaking up and getting people's attention, ask that person if they would help you in your role as a caregiver. Perhaps another family member could accompany you and your care receiver to appointments, or give you some advice on how to address the issue with your employer.

Advocating for all caregivers

You can support all caregivers by talking to people in your community about your experience. You can also help to work toward positive change by talking about your caregiving with your Member of the Legislative Assembly (MLA) or your Member of Parliament (MP). Tell your MLA or MP about your experiences of caregiving. Describe how existing programs and services have helped you and how they might be improved to better serve all caregivers.

Contact information for your MLA is available at:

Web: www.gov.ns.ca/legislature
Phone: (902) 424-5200
Toll-free: 1-800-670-4357

Contact information for your MP is available at:

Web: www.canada.gc.ca/directories/direct_e.html
Toll-free: 1-800-622-6232

Policies for Caregivers

There are also organizations that work to influence public policy on behalf of all caregivers:

The Canadian Caregiver Coalition

The Canadian Caregiver Coalition is a not-for-profit organization that works with the federal government to develop public policy on behalf of caregivers. Its mission is to join with caregivers, service providers, policy makers and other stakeholders to identify and respond to the needs of caregivers in Canada.

For more information, contact the Canadian Caregiver Coalition:

Web: www.ccc-ccan.ca
Toll-free: 1-888-866-2273

Caregivers Nova Scotia

Caregivers Nova Scotia Association is dedicated to providing recognition and practical supports to friends and family giving care. It also participates in various government Task Forces and Working Groups to help influence public policy for the benefit of caregivers.

For more information, see a complete description of the Association on page v, or contact Caregivers Nova Scotia:

Web: www.caregiversNS.org
Toll-free: 1-877-488-7390
Halifax: (902) 421-7390

Legal Issues

This section offers a brief overview of some of the legal issues that are commonly faced by caregivers. It is important to note that the laws are different in each province and territory – the information in this section applies only to Nova Scotia.

Most of the legal documents discussed in this section can be created using 'fill-in-the-blank' forms that are available at stationery or drug stores. However, it is always best to get advice from a professional. Of course, it can also be very expensive.

In Nova Scotia, there are a few ways to get your legal questions answered for little or no cost. The following resources and programs are all offered by the Legal Information Society of Nova Scotia.

On the web

The Legal Information Society of Nova Scotia has a website with detailed information about each of the topics discussed here, and much more.

Web: www.legalinfo.org

By phone

Dial-a-Law provides legal information on a taped message service 24 hours a day. You can use the keypad on your phone to select a topic and listen to a recording about a specific area of the law. This is a free service that may help to answer your questions about a particular legal concern.

(902) 420-1888 (not toll-free)

The *Legal Information Line* is a free service. If you have a question about the law, call the toll-free number at 1-800-665-9779. They will try to answer your question and tell you where to get help with legal problems.

Lawyer Referral Service

If you have additional questions or concerns about any of the topics in this section, it will likely be helpful for you to talk to a lawyer. In Nova Scotia, the Lawyer Referral Service will give you the name and telephone number of a lawyer who will meet with you for 30 minutes for a fixed fee of $20 plus tax. During this time, you can discuss your situation and get an idea of what your options are and what costs are involved.

Toll-free: 1-800-665-9779
Halifax: (902) 455-3135

Power of Attorney

What is it?

A Power of Attorney is a legal document that allows you to name a person to make decisions on your behalf about money, assets, debts, and property. These decisions must be made for your benefit. Decisions about medical care can also be part of a Power of Attorney, or they may be separate in an Advance Health Care Directive, which is explained on page 43.

Why is it important?

By law, any Nova Scotians aged 19 or older are assumed to be able to make their own decisions. However, an illness or accident can result in losing that ability, making it necessary for someone else to make decisions for you. This authority comes from you in a Power of Attorney.

How do I make one?

You can get a 'fill-in-the-blank' Power of Attorney form at stationery or drug stores. These documents are not expensive and may be appropriate for many situations. However, if you own property such as a house, a cottage, or a camp, or if you own property outside Nova Scotia, you may need help from a lawyer.

What if I don't have one?

If you are not able to make decisions because of an illness or injury and you don't have a Power of Attorney, someone must go to court and ask to make decisions on your behalf. This is called guardianship of the estate. The person does not have to be a family member, and this court process is more time consuming and expensive than creating a Power of Attorney document by yourself or with a lawyer in advance.

Advance Health Care Directive
(commonly referred to as a Living Will)

What is it?

There are two basic types of Advance Health Care Directives – a **proxy directive** and an **instructional directive**.

In a **proxy directive**, you name a person as your proxy and give him or her authority to make health care decisions for you should you become unable to consent to treatment.

In an **instructional directive**, you set out your wishes for what health care measures you want to be taken for you should you become unable to consent to treatment.

You may combine both types of directives in your Advance Health Care Directive, or you may choose to have only one type of directive.

Why is it important?

By law, any Nova Scotian aged 19 or older are assumed to be able to make decisions about their own medical treatment. However, an illness or accident can result in losing that ability, making it necessary for someone else to make decisions for you. This authority comes from you in a written document called an Advance Health Care Directive.

How do I make one?

You can get an Advance Health Care Directive at many stationery or drug stores. They are not expensive and may be useful in many situations. However, the safest way to make this document is with a lawyer. You should also talk with your family doctor about who will make your medical decisions and how to guide them.

What if I don't have one?

If you don't have an Advance Health Care Directive, your next of kin will often be involved in making medical decisions for you. This may or may not be ideal. If you want to ensure a particular person has the authority to speak on your behalf, you must name them in an Advance Health Care Directive.

If there is a dispute among family members, someone must go to court and ask to make decisions about your medical care on your behalf. This is called guardianship of the person. The person does not have to be a family member. This court process is more time consuming and expensive than creating an Advance Health Care Directive document by yourself or with a lawyer in advance.

Joint Ownership

When one person is the owner of property or money, that person determines how the property is used or how the money is spent. In the case of *joint ownership*, more than one person can make these decisions. The two most common forms of joint ownership for caregivers are jointly owning a bank account and jointly owning a home.

Bank account

Usually the person named as the owner of a bank account can deposit money and take money out. Exactly what an owner can do is spelled out in their agreement with the bank. Often spouses have a joint account. They both put money in, and they both take money out.

In many families, a parent may invite an adult child to become a joint bank account owner to help with banking in times of illness or if the parent has trouble getting to the bank. In these situations, it is usually only the parent who is putting money into the account, and the child can take money out to pay the parent's bills.

Pros and cons

While it is convenient for a caregiver and care receiver to have a joint bank account, there may be pitfalls. Here are a few tips for you and your care receiver.

1. The care receiver should have complete trust in someone before adding him or her as an owner of the care receiver's bank account.
2. The care receiver should tell the joint owner what the money is to be used for and when. If the care receiver is the only person putting money in, it should be made clear that the money can only be used for the care receiver. It may be useful to write up an agreement between the care receiver and the joint owner.

3. If you are a caregiver for your parent and you are one of several siblings, you should be aware that your actions are open to scrutiny by the other siblings. Anything you do with the money must be for the benefit of the care receiver.
4. Discuss what is to happen to any money left in the bank account if one of the joint owners dies. For example, if the care receiver dies and has been the only person putting money into the account, is the money meant to go to the surviving owner or to pass through the will? For everyone's sake, make your intentions clear to the whole family.

House

Owning a major asset such as a home is significant. Generally the owner can borrow money against it or sell it. There can be more than one owner, but it is the surviving owner of the home who inherits the property.

Many couples own their home together in a special type of ownership called *joint with right of survivorship*. This means that the surviving spouse inherits the home automatically. The transfer of ownership requires less paperwork and is easy and cost effective.

Often a widowed parent will invite an adult child to become a joint owner of the home in which the parent lives. In some cases, there is an understanding that the caregiver will inherit the house in exchange for giving lifetime care to the parent.

Pros and Cons

In spite of being cost effective and easy, there are some reasons not to own a home jointly:

1. Each owner must sign all documents required to deal with the house. For example, to borrow money against the house or to sell it, the child must agree with the parent's wishes even though the parent may still consider the house to be his or her sole property.
2. The property becomes part of the child's financial affairs, so the home in which the parent lives could become part of a divorce or business bankruptcy of the child.
3. Anyone who owns more than one residence may have to pay extra income tax. If you own a home and are invited by your care receiver to become a joint owner, you should consult a taxation expert before agreeing.

Why is this important for caregivers?

If the goal of joint ownership is to have the family caregiver inherit the house, make sure this intention is clear to all family members and get legal advice.

Will

What is it?

A Will spells out how you want to give away your money and property after your death. You also name your Executor, the person who will carry out your instructions.

Why is this important for caregivers?

If you are a family caregiver, try to make sure your care receiver has an up-to-date Will. Often it is the caregiver who plays a major role in distributing the care receiver's property after death. This is a difficult and time-consuming task made more complex by the stresses of long-term caregiving. Having a current Will can make the task easier.

How do I make one?

You can get a Will form at many stationery and drug stores. These are not expensive and are appropriate for many situations. However, the safest way to make a Will is to hire a lawyer. In some cases, you are required to hire a lawyer to advise you through this process (for example, if you own property in a different province or country).

What happens if I don't have one?

If you don't have a Will, the rules of the province will be used to give away your money and property. One of your family members will be the Executor. You might not agree with the rules or be unhappy with the idea of a certain family member becoming your Executor. To make sure your wishes are respected, you should have a Will.

Financial Matters

This section offers a brief overview of some existing programs and policies that may benefit some caregivers or their care receivers. Caregiving can have a significant impact on the financial well-being of caregivers, whether it is because of immediate costs related to the care provided, or because of lost pension income many years later.

Over recent years, both the provincial and federal governments, along with other countries around the world, have increasingly recognized the contributions of caregivers and the financial burden that many experience. There is work underway by a variety of individuals and organizations to advocate for more policies and programs that could help to recognize the value of caregiving.

Critical Illness Insurance

What is it?

Critical illness insurance pays a lump sum to you if you suffer a specific illness and survive. This money can help to pay for many things including medical expenses, home health care, home modifications, or other therapies or medications. You don't have to get approvals for these items or provide receipts.

Why is this important for caregivers?

Caregivers can also become ill and need care. If you don't have family members to help, you might have to think about the expense of hiring someone else to care for you and your care receiver.

Pros and Cons

You should take a close look at the details of any policy you are considering. Some things to look for include:

1. A clear definition of what an illness or accident is and which ones are covered by the policy. For example, policies may cover certain types of cancer and not others. You don't want to pay for coverage and then find out that many illnesses are excluded.
2. Most policies will pay benefits if you suffer one of the following: heart attack, stroke, coronary bypass surgery, and some cancers.
3. Some policies will pay benefits if you suffer from one of the following: multiple sclerosis, Parkinson's disease, major organ transplant, severe burns, loss of limb, and loss of sight or hearing.
4. Check to see how long it takes to get paid. Many policies will pay benefits 30 days after the illness starts.

How to get more information

Ask your financial advisor or an insurance agent. Some employers may also offer Critical Illness Insurance as an employee benefit.

Long-Term Care Insurance

What is it?

The purpose of long-term care insurance is to help pay the costs of care either in a nursing home or at home. It can give families options when choosing what type of care is needed or where that care will be provided.

Why is this important for caregivers?

If a care receiver has long-term care insurance, it can offer additional options and resources for the caregiver.

Caregivers may also want to consider long-term care insurance, since they can also develop long-term health conditions just like anyone else. If you become ill and don't have family members to help, you might have to hire someone else to give care to you and to your care receiver.

Pros and Cons

In Canada, this insurance is relatively new. You should take a close look at the details of any policy you are considering.

Remember:

1. Be careful about the rules for hiring people to help in the home. If the policy states you must hire someone with minimum qualifications or education, then make sure there are people in your community who meet these criteria.
2. This insurance can be expensive. In some families the children get together to pay for the insurance for their parents.

How to get more information

Ask your financial advisor or an insurance agent. Some employers may also offer Long-Term Care Insurance as an employee benefit.

The Council on Aging in Ottawa also has an excellent booklet called *Long-Term Care Insurance in Canada: What is it and do I need it?* This can be downloaded from their website at www.coaottawa.ca/index_e.html or borrowed from the library at Caregivers Nova Scotia (phone 421-7390 or toll-free 1-877-488-7390).

Compassionate Care Benefit

What is it?

The Compassionate Care Benefit is part of the Employment Insurance (EI) program. It provides a paid leave of up to six weeks for employees who need time to care for a gravely ill family member. The benefit covers part of your salary, and there is a two-week waiting period after you apply for the benefit before payments begin.

To qualify, you must be eligible for EI and provide a medical certificate stating that the family member has a "significant risk of death" within six months. The ill family member may be your spouse or common-law partner, child, parent, grandparent, aunt, uncle, niece, nephew, or anyone you consider as family, including a close friend or neighbour.

The Compassionate Care Benefit claim may be shared. For example, if you and your two sisters wanted to share the care of your ill father, you may share the claim if each of you qualifies for EI and your combined leave does not exceed the six-week limit.

Pros and Cons

Before deciding to take a leave and claim a Compassionate Care Benefit, you should consider the following:

1. Will the reduced income cover your own expenses and additional expenses including nursing care, prescriptions, and treatments not covered by health insurance?
2. Check with your employer or union to see if your group medical benefits remain in effect while you are on leave.

How to get more information

Visit the Service Canada website at:

www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml

or call Service Canada toll-free at 1-800-622-6232 and ask to speak to someone about the Compassionate Care Benefit.

Services in Nova Scotia

There are many different services offered to caregivers and care receivers. This section offers a brief overview of existing services and contact information to help you connect with the services you may need or want.

Some of the services listed in this section may be available for free or at a reduced cost depending on your family size and income.

It's important to remember that navigating your way through the health care system and coordinating services for you or your care receiver is not easy. You may find yourself disappointed and frustrated with the inflexibility, inconvenience and lack of availability of many services.

You'll notice from the comments below that many of the existing services can be extremely helpful or not helpful at all!

We found out about home care, and we've been getting that and it's been the greatest.

We have a whole list of [home care workers], oh my goodness... I don't like this idea and Arnold doesn't like it neither because every time we have a new one then we have to explain the whole thing all over again.

Government Services

Services offered by government agencies are often provided for no or low cost to the client. Below is a brief overview of five government agencies which offer services that may be useful for caregivers and for care receivers.

The **Nova Scotia Department of Community Services** has two main program areas that coordinate services that may be useful for caregivers.

- Services for Persons with Disabilities is a program that provides residential and day programs for adults with intellectual/physical disabilities or long-term mental illness. Residential services include a continuum of options ranging from support to families caring for a family member with a disability in their own home, to full 24-hour residential support.
- Housing Services can help lower-income households maintain, acquire, or rent safe, adequate and affordable housing. The program also offers grants and loans for home repairs, adaptations and additions.

These services can be accessed by calling toll-free 1-877-424-1177, or visiting the website for more information:

www.gov.ns.ca/coms

The **Continuing Care Branch** of the Nova Scotia Department of Health provides access to a range of services such as home care, long-term care, respite options, home oxygen, palliative care, self-managed care, and adult protection services. These services can be accessed by calling toll-free 1-800-225-7225 (or 1-902-424-4288 for out-of-province callers). A person at this number will help you identify your needs for care and the services that would best meet them. This number operates everyday including weekends, from 8:30 a.m. to 4:30 p.m. Visit the website for more information: www.gov.ns.ca/heal/ccs.

The Nova Scotia's **Seniors' Secretariat** provides a single entry point to government that can respond to seniors' issues and concerns. The Secretariat offers a Toll-Free Information line which allows seniors, as well as concerned family members and friends, to call for help in accessing information dealing with government services and programs. The province-wide toll-free number is 1-800-670-0065 (or 424-0065 in Halifax/Dartmouth), or visit the website for more information: www.gov.ns.ca/scs.

The **First Nations and Inuit Home and Community Care Program** offers essential Home Care services in each of the 13 First Nations communities in Nova Scotia. This service is for First Nations individuals who live on reserve. For more information, please call 1-902-564-5283.

The **Veterans Independence Program** (VIP) is a national home care program offered by Veterans' Affairs Canada. If you or the person you care for is a veteran, you may qualify for VIP services such as grounds maintenance, housekeeping, personal care services, nutrition services, health and support services, out-patient health care, transportation, home adaptations, and nursing home care. For more information, contact Veterans' Affairs Canada toll-free at: 1-866-522-2122 (English) or 1-866-522-2022 (French) or visit the website at www.vac-acc.gc.ca.

Respite

Respite is intended to give caregivers a break or to offer replacement care if a caregiver needs it because of because of work-, family-, or health-related reasons. Respite can be provided by another friend or family member, or by a health care professional. It can be provided in the care receiver's home, or in a care facility, for varying amounts of time from a few hours to several days or weeks.

In Nova Scotia, the Department of Health coordinates in-home respite and licensed respite beds in long-term care facilities across the province. For more information, call: **Continuing Care** at 1-800-225-7225.

For families caring for adults or children with disabilities, the **Department of Community Services** offers a variety of programs that provide support either in your home or in a care facility. Contact them toll-free at 1-877-424-1177 for more information.

In either case, it can take up to several weeks for the agency to complete an assessment. Call as early as possible.

Other agencies that offer respite care:

Veterans' Affairs Canada
(see complete description on page 59)
Toll-free: 1-866-522-2122

Victoria Order of Nurses (VON)
(902) 453-5800
(see complete description on page 63)

Private Agencies

Several private agencies also offer respite services. Check your local telephone book under 'Home Health Care - Services.'

Caregivers Nova Scotia Association may also be able to answer your questions about Respite. See page v for a complete description, or contact them toll-free at 1-877-488-7390 or in Halifax at (902) 421-7390.

Home Care

The Department of Health, Continuing Care Branch provides community-based health care services and assistance with the daily activities of living to Nova Scotians of all ages who require support to stay in their homes for as long as it is safely possible.

Home care can range from help with daily living tasks and personal care to light housekeeping, nursing services, home oxygen, and palliative care.

If you require an assessment for home care, you should contact the Continuing Care Branch of the Department of Health. A care coordinator will then arrange for a time to meet with you to complete the assessment.

Depending on your family's income and size, there may be a charge for services. Contact the Department of Health's Continuing Care Branch toll-free at 1-800-225-7225.

Other agencies that offer home care:

Veterans' Affairs Canada
Veterans' Affairs Canada offers the Veterans Independence Program (VIP), which is a home care program established to help clients remain healthy and independent in their own homes or communities.

1-866-522-2122 (English) or
1-866-522-2022 (French)
or visit their web site at www.vac-acc.gc.ca

The Victoria Order of Nurses (VON)
See a complete description and contact information for the VON on page 63.

Private agencies
Some private agencies also offer home care services. Check your local telephone book under 'Home Health Care - Services.'

Equipment, Assistive Devices & Medical Supplies

Abilities Foundation of Nova Scotia
The Abilities Foundation of Nova Scotia has an Assistive Devices Program that offers financial assistance for devices such as walkers, orthotics, wheelchairs, and various other medical devices. Some equipment is available for loan, and a Wheelchair Recycling program is available to adults and children who require a new or replacement wheelchair.

3670 Kempt Road
Halifax, NS B3K 4X8
Phone: (902) 453-6000
Web: www.abilitiesfoundation.ns.ca

Canadian Red Cross Society
The Canadian Red Cross Society offers free lending services for medical equipment such as walkers, wheelchairs, raised toilet seats, commode chairs, crutches, and more.

Phone: (902) 423-3680 (Halifax)
Web: www.redcross.ca

Several other companies sell or rent health care equipment and supplies. Try contacting your local Legion, Lions' Club, drug store, or pharmacy. Check your local telephone book under 'Home Health Care – Equipment & Supplies.'

Transportation

Dial-a-Ride Nova Scotia
Dial-a-Ride is a support network of non-profit, community-based transportation systems located throughout mainland Nova Scotia. When you call, Dial-a-Ride will connect you with transportation services in your area.

Toll-free: 1-877-305-7433

Handi-Trans
Handi-Trans is operated by the Cape Breton Regional Municipality and offers accessible public transportation services to persons in Cape Breton with mobility impairments. Passengers are advised to make reservations five days in advance.

Phone: (902) 539-4336

Other local transportation services may exist in your community. Contact the VON (see page 63) or your local hospital and ask about transportation services in your area.

Accessible Parking

The Registry of Motor vehicles distributes accessible parking plates and permits to qualified individuals with mobility impairments. There is no charge.

For more information, contact:

(902) 424-5851 (Halifax)
Toll-free 1-800-898-7668

Meals

For specific information on meal programs in your area, contact the **Continuing Care** toll-free line at 1-800-225-7225, or the Nova Scotia Meals Network representative nearest you:

Central Nova Scotia
Deborah Dostal
Spencer House Senior Centre
Halifax, NS
(902) 421-6131

Eastern Nova Scotia
Joan Fownes
Victoria County Hospital
Baddeck, NS
(902) 295-2112

Northern Nova Scotia
Sheila Hoeg
VON New Glasgow
(902) 755-4524

Western Nova Scotia
Vivian MacMillan
Windsor, NS
(902) 798-4913

The Nova Scotia Meals Network also publishes a directory of meal programs including Meals on Wheels, Wheels to Meals, and Private Recipe Frozen Meals. The directory is available by calling the Continuing Care toll-free line at 1-800-225-7225.

Housecleaning/Maintenance

Some agencies that offer home nursing care may also provide some housecleaning and maintenance (see 'Home Care' on page 58). Private companies also offer housecleaning services. See 'House Cleaning' and/or 'Maids' & Butlers' Service' in your local telephone book.

Home Improvements, Modifications and Renovations

Several grant and loan programs are offered through the Department of Community Services, Housing Services to help lower-income Nova Scotians maintain, repair, or modify their homes to accommodate the needs of care receivers. For more information, or to apply for a grant or loan, contact the Housing Services Office nearest you:

Cape Breton Region
Toll free: 1-800-567-2135

Central Region
Toll free: 1-800-933-2101

Metro Region
Toll free: 1-800-774-5130

Western Region
Toll free: 1-800-278-2144

Housing

The Nova Scotia Department of Community Services provides a variety of housing programs and options through their Housing Services division. These programs range from Licensed Homes for Special Care to Seniors Rental Housing, and most programs require an assessment to determine your eligibility. For more information about housing options in Nova Scotia, contact the Department of Community Services at 1-877-424-1177.

The Department of Health, Continuing Care Branch also coordinates some nursing homes, residential care facilities and community-based options. For more information, contact the Department of Health, Continuing Care Branch at 1-800-225-7225.

Adult Day Programs

Adult day programs offer away-from-the-home care usually during regular working hours. Programs are usually held in local hospitals or community centres, and the services they provide can vary, but may include health monitoring, foot care, hair styling, exercise, information sessions, group outings, and social events.

To find an Adult Day Program in your area, contact Caregivers Nova Scotia toll-free at 1-877-488-7390 or in Halifax at (902) 421-7390.

Other Programs & Services

VON

The Victoria Order of Nurses (VON) is a not-for-profit, national health care organization and registered charity offering a wide range of community health care solutions 24 hours a day, seven days a week. Their home health care services include palliative care, pediatric services, dialysis, foot care, and more. Other support services they offer include personal care, light housekeeping, meal preparation, and respite care. Visit the VON website at www.von.ca or contact the VON Branch nearest you for more information:

Annapolis Valley	(902) 678-3415
Antigonish	(902) 863-5700
Cape Breton Metro	(902) 564-6479
Colchester East Hants	(902) 893-3803
Cumberland	(902) 667-8796
Greater Halifax	(902) 453-5800
Lunenburg County	(902) 624-1897
Pictou	(902) 752-3184
Queens County	(902) 354-3297
Tri-County	(902) 742-8962

Personal Response Services

A personal response service usually consists of a personal help button worn around the wrist or neck. When the button is pressed, help is summoned based on your pre-arranged instructions. A personal response service can be life-saving and is especially important for people who live alone. There are a number of private and not-for-profit organizations that offer a personal response service in Nova Scotia. To find out more, contact Caregivers Nova Scotia (see page v).

Vial of Life

The Vial of Life provides emergency medical personnel with vital and perhaps life-saving medical information about you if they are called to your home and find you unconscious or very ill. The vial is a small plastic container. It contains a specially designed form on which you record information such as your name, health card number, medical history, doctor's name and phone number, and a contact person. The vial is kept inside your fridge and a Vial of Life sticker is placed on the outside of your fridge to alert emergency personnel that vital medical information is available. Thanks to the efforts of local sponsors, the Vial of Life kits are now available free of charge in many communities. To find out whom to contact in your area, call the Seniors' Secretariat at 1-800-670-0065.

Information and Support

You have to arm yourself with information.

In addition to the agencies that offer services, a number of organizations provide information and support for caregivers in Nova Scotia.

Caregivers Nova Scotia

Caregivers Nova Scotia is dedicated to providing recognition and practical supports to friends and family giving care. The Association is non-profit, with a volunteer board of directors and a staff of three. Their services for caregivers take many forms, including workshops, informative newsletters focused on caregiving issues, a book and video lending library, telephone caregiver assistance, community-based peer support groups, and a website with an e-forum where caregivers can connect with each other.

Phone: (902) 421-7390
Toll-free: 1-877-488-7390
Web: www.caregiversns.org

Glow With Us

Every year on October 1st, Caregivers Nova Scotia invites everyone to put up festive lights in the windows of their homes to spotlight family and friend caregivers who often feel isolated and invisible. For more information, visit www.caregiversns.org

Canadian Caregiver Coalition

The Canadian Caregiver Coalition is the national voice for the needs and interests of family caregivers. They are a bilingual, not-for-profit organization made up of caregivers, caregiver-support groups, national stakeholder organizations, and researchers.

Phone: 1-888-866-2273 (toll-free)
Web: www.ccc-ccan.ca

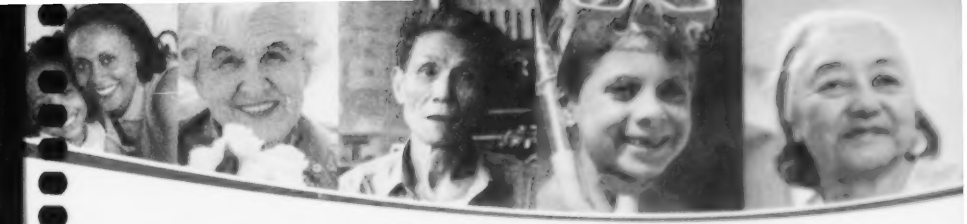
Diagnosis-specific Organizations

Several non-profit organizations provide support and information about specific health-related conditions (e.g., Alzheimer Society, Heart and Stroke Foundation, Canadian Diabetes Association). Check your local telephone book under "Charitable & Non-Profit Organizations."

Family Resource Centres

Family Resource Centres across the province can be excellent sources of information and support. There are 38 centres in Nova Scotia, each offering a range of services to its surrounding community. Some examples of the services that may be offered by a Family Resource Centre include: parent education and childcare, breakfast programs, employment support programs, workshops on a variety of topics, and referrals to other services in the community. To find the Family Resource Centre nearest you, contact the Nova Scotia Council for the Family:

Suite 602, 5121 Sackville Street, Halifax, NS B3J 1K1
Phone: (902) 422-1316
Web: www.nscouncilfamily.org



Women's Centres CONNECT!

Women's Centres Connect! is the collective voice of the eight Women's Centres in Nova Scotia. Connect! provides coordination and information to Women's Centres and articulates their activities, needs and concerns. Each of the Centres offers unique services for the women in their communities, and all of the Centres offer:

- Information & Referral
- Advocacy & Accompaniment
- Individual Support Counselling & Crisis Intervention
- Resource Library
- Community Education
- Outreach
- Programs

The eight Women's Centres are located in:

Antigonish – Antigonish Women's Resource Centre
Phone: (902) 863-6221

Bridgetown – The Women's Place
Phone: (902) 665-5166

Lunenburg – Second Story Women's Centre
Phone: (902) 543-1315 or (902) 640-3044

New Glasgow – Pictou County Women's Centre
Phone: (902) 755-4647

Sheet Harbour – LEA Place Women's Resource Centre
Phone: (902) 885-2668

Sydney – Every Woman's Centre
Phone: (902) 567-1212 or (902) 567-1911

Truro – Central Nova Women's Resource Centre
Phone: (902) 895-4295

Yarmouth – Tri-County Women's Centre
Phone: (902) 742-0085

Other professional services you may wish to access:

Transition Planning: There are a number of health care professionals who provide support to people who are getting ready to be discharged from hospital. In some major hospitals, a Discharge Planner is available to help prepare patients to go home, while in smaller hospitals and other health care settings, there is often a doctor or nurse who has experience in this area. Ask a nurse or doctor if there is someone in the hospital to help with your transition planning. These professionals often provide information and referrals to other services such as home care, home oxygen, in-home meals programs, or the Victoria Order of Nurses (VON).

Support Groups offer caregivers an opportunity to meet and support each other, and to share ideas, resources and information. For information on support groups in Nova Scotia that are currently active, call Caregivers Nova Scotia:

In Halifax: (902) 421-7390
Toll-free: 1-877-488-7390

Some agencies offer information, programs or services for specific groups. If you or the person you are caring for is:

Acadian or Francophone

La Fédération Acadienne de la Nouvelle-Écosse
www.federationacadienne.ca
(902) 433-0065

Fédération des Femmes Acadiennes de la Nouvelle-Écosse
www.ffane.ca
(902) 433-2088

Regroupement des aîné(e)s de la Nouvelle-Écosse
(902) 433-0065

Réseau Santé - Nouvelle-Écosse
Email: reseau@reseausanteNE.ca

Office of Acadian Affairs
www.gov.ns.ca/acadian
(902) 424-0497

African Canadian

Health Association of African Canadians
(902) 405-HAAC (4222)
www.haac.ca

Office of African Nova Scotian Affairs
(902) 424-5555
Toll-free: 1-866-580-ANSA (2672)
www.gov.ns.ca/ansa

Aboriginal

Nova Scotia Native Women's Association (Truro)
http://nsnwa.tripod.com
(902) 893-7402

Mi'kmaq Family and Children's Services (Shubenacadie)
Phone: (902) 758-3553
Toll-free: 1-800-263-8686

Mi'kmaq Native Friendship Centre
(902) 420-1576

Eskasoni Community Health Centre
www.eskasonihealth.ca
(902) 379-3200

The Confederacy of Mainland Mi'kmaq
www.cmmns.com
(902) 895-6385

Office of Aboriginal Affairs
www.gov.ns.ca/abor
(902) 424-7409

Union of Nova Scotia Indians
www.unsi.ns.ca
(902) 539-4107

Health Canada – First Nations and Inuit Health Branch
www.hc-sc.gc.ca/fnih-spni/index_e.html
Halifax: (902) 426-6201

Native Council of Nova Scotia
www.ncns.ca
Toll-free: 1-800-565-4372
In Truro: (902) 895-1523

Child under the age of 19

IWK Health Centre
www.iwk.nshealth.ca
(902) 470-8888

Immigrant or Newcomer

Metropolitan Immigrant Settlement Association (MISA)
www.misa.ns.ca
(902) 423-3607

YMCA Newcomer Service Centre
(902) 457-9622

Centre for Diverse Visible Cultures
www.immigrants.ca
(902) 445-0946

Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ)

Nova Scotia Rainbow Action Project
www.nsrap.ca

Canadian Rainbow Health Coalition
1-800-955-5129
www.rainbowhealth.ca

Cape Breton Gay and Lesbian Equality Association
Email: cbglea@yahoo.ca

South Shore Pride
www.southshorepride.ca
(902) 685-3297

Person with a disability

reachAbility
www.reachability.org
Phone: (902) 429-5878
Toll-free: 1-866-429-587

Nova Scotia League for Equal Opportunities
www.nsnet.org/leo
Toll-free: 1-866-696-753

Nova Scotia Disabled Persons Commission
www.gov.ns.ca/disa
Toll-free: 1-800-565-828
TTY: 1-877-996-9954

Senior Citizen

Seniors' Secretariat

The Seniors' Secretariat is the provincial government agency responsible for coordinating the planning and development of policies, programs and services for seniors. They publish the Programs for Seniors directory with contact information for a wide range of programs and services for seniors in Nova Scotia. For a copy of Programs for Seniors or for other information, contact the Seniors' Information Line at 1-800-670-0065 (Halifax (902) 424-0065).

Terminally Ill

Living Lessons Help Line
1-877-203-INFO
www.living-lessons.org

Canadian Hospice Palliative Care Association
Toll free 1-800-668-2785
www.chpca.net

Nova Scotia Hospice Palliative Care Association
(902) 893-7171
www.nshpca.ca

Veteran

Veterans' Affairs Canada
1-866-522-2122 (English)
1-866-522-2022 (French)
www.vac-acc.gc.ca

Reading List

Healthy Balance Research Program Publications

1. *A Portrait of Unpaid Care in Nova Scotia.*
   J. Keefe, G. Hawkins & P. Fancey (2006)
   Available at: www.healthyb.dal.ca/reports.html

2. *Snapshots of the Lives of Caregivers: "I do it because I love her and I care."*
   B. Beagan, R. Stadnyk, C. Loppie, N. MacDonald, B. Hamilton-Hinch & J. MacDonald (2006)
   Available at: www.healthyb.dal.ca/reports.html

3. *Caregiver Portraits: Narratives of 14 Women Caregivers in Nova Scotia.*
   B. Beagan, B. Hamilton-Hinch, C. Loppie, J. MacDonald, N. MacDonald & R. Stadnyk (2005)
   Halifax, NS: Healthy Balance Research Program

4. *Caregiver Resilience and the Quest for Balance: A Report on Findings from Focus Groups.*
   J. Gahagan, C. Loppie, M. MacLellan, L. Rehman & K. Side (2004)
   Available at: www.healthyb.dal.ca/reports.html

5. *Policy Options to Support Dependent Care: The Tax/Transfer System.*
   R. Shillington (2004)
   Available at: www.healthyb.dal.ca/reports.html

6. *The Healthy Balance Research Program: Knowledge Translation for Women's Unpaid Caregiving.*
   C. Amaratunga, B. Neumann & B. Clow (2006)
   CIHR Institute of Population and Public Health Knowledge Translation Casebook
   Ottawa, ON: Canadian Institutes of Health Research
   Available at: www.irsc.gc.ca/e/30747.html#a

7. *Thinking it Through: Women, Workand Caring in the New Millennium.*
P. Armstrong & H. Armstrong (2001
Available at: www.healthyb.dal.ca/eports.html

8. *Women's Unpaid Caregiving and Sress.*
C. Brannen (2006)
Centres of Excellence for Women's Health Research
Bulletin 5(1)
Available at: http://www.cewh-cesf:a/en/publications/RB/v5n1/page5.shtml

9. *Total Caregiving Policy Package forWomen in the Canadian Forces.*
C. Brannen, K. Petite & S. Martin (2005)
Halifax, NS: Healthy Balance Reseach Program

10. *Children with Disabilities and Chroic Conditions and Longer-Term Parental Health.*
P. Burton, L. Lethbridge & S. Phipps(in press)
Journal of Socio-Economics

11. *Mothering Children with Disabilitie and Chronic Conditions: Long-Term Implications for Self-Reported Health.*
P. Burton, L. Lethbridge & S. Phipps(in review)
Canadian Public Policy

12. *Taking its Toll: The Influence of Paicand Unpaid Work on Women's Well-Being.*
M. MacDonald, S. Phipps & L. Lethridge (2005)
Feminist Economics 11(1), 63-94

13. *Total Packages of Work: Women Living in Atlantic Canada Compared to the Rest of Canada.*
M. MacDonald, S. Phipps & L. Lethridge (2005)
Atlantis 30(1), 105-121

14. *Promoting Good Health Among Caregivers: Reflections from the Healthy Balance Research Program in Canada.*
B. Neumann (2007)
In U. Walter & B. Neumann (Eds.) Gender in Prevention and Health Promotion: Policy, Research, Practice. Austria: Springer-Verlag.

15. *A Healthy Balance: Applied Research on Women's Paid Work and Unpaid Caregiving in Nova Scotia, Canada.*
B. Neumann (2006)
In V. Lasch, W. Freitag & U. Sonntag (Eds.) Gender, Health and Cultures.
Kassel, Germany: Kassel University Press, 97-118

16. *Equity Reference Groups: Creating Linkages to Marginalized Communities for Research and Knowledge Translation.*
B. Neumann (2006)
In W. Ernst & U. Bohle (Eds.) Transformationen von Geschlechterordnungen in Wissenschaft und anderen sozialen Institutionen. Hamburg: Lit Verlag, 168-180

17. *Supporting Caregivers of Dependent Adults in the 21st Century.*
B. Rajnovich, J. Keefe & J. Fast (2005)
Available at: www.healthyb.dal.ca/reports.html

18. *A Healthy Balance: A Summary Report on a National Roundtable on Caregiving Policy in Canada.*
J. Varga-Toth (2005) based on the research findings of C. Amaratunga, B. Neumann and B. Clow
Ottawa, ON: Canadian Policy Research Network
Available at: www.coag.uvic.ca/eolcare/documents/SummaryReportCGinCanada_000.pdf

Further Reading

19. *Informal Caregiving: Is It Really Cheaper?*
J. Fast & J. Frederick (1999)
Paper presented at the International Association of Time Use Researchers Conference, Colchester, England
Available at: www.iser.essex.ac.uk/conferences/iatur/1999/pdf/paper4.pdf

20. *Caregiver's Handbook.*
R. Torres-Stanovik (Ed.)
San Diego, CA: San Diego County Mental Health Services
Available at: www.seniormag.com/caregiverresources/handbook/index.htm

21. *Programs for Seniors 2007.*
Nova Scotia Seniors' Secretariat
Available at: www.gov.ns.ca/scs/programs.asp

22. *The Complete Canadian Eldercare Guide: Expert Solutions to Help You Make the Best Decisions for Your Loved Ones.*
C. Tapp-MacDougall (2004)
Mississauga, ON: John Wiley & Sons Ltd.

23. *Because We Care: A Guide for People Who Care.*
U.S. Department of Health and Human Services
Available at: www.aoa.gov/prof/aoaprog/caregiver/carefam/taking_care_of_others/wecare/we-care.pdf

24. *Where to Begin: An Introductory Planning Guide for Family Caregivers.*
Caregivers Nova Scotia
Toll-free: 1-877-488-7390

25. *A Guide for Caregivers.*
Canadian Hospice Palliative Care Association
Available at: www.living-lessons.org/resources/secured/caregiver.asp

26. *A Guide for the Caregiver.*
Manitoba Health & Manitoba Seniors' and Healthy Aging Secretariat
Available at: www.gov.mb.ca/shas/pdf/guide_for_caregiver_05.pdf

27. *Give Me a Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite.*
Canadian Association for Community Care (2002)
Available at: www.cacc-acssc.com/english/pdf/exec.pdf

28. *Family Caregiver Centre.*
Calgary Health Region
Web resources available at: www.familycaregivers.ab.ca/

29. *Family Caregiving 101.*
American National Family Caregivers' Association
Web resources available at: www.familycaregiving101.org/

If you are looking for additional reading about caregiving, please note that Caregivers Nova Scotia maintains a library of materials on the subject. You can visit their office in Halifax or view a list of their materials online and request items to be mailed to you:

Caregivers Nova Scotia
7001 Mumford Rd, Tower 1, Suite 105
Halifax, NS B3L 4N9
Phone: (902) 421-7390
Toll-free: 1-877-488-7390
Email: support@caregiversns.org
Web: www.caregiversns.org

It may be helpful for you to fill in this page so that you have easy access to this information when you need it.

Information about you:

Name:

Address:

Home Phone:

Work Phone:

MSI Number:

Family Doctor:

Pharmacy:

Health Insurance Company:

Policy Number:

Information about your care receiver:

Name:

Address:

Home Phone:

Work Phone:

MSI Number:

Family Doctor:

Pharmacy:

Health Insurance Company:

Policy Number:

EMERGENCY (Ambulance, Police, Fire)
9-1-1

Frequently Called Numbers

Local hospital:

Pharmacy:

Doctor:

Lawyer:

Health Insurance:

Caregivers Nova Scotia:
Toll-free 1-877-488-7390
In Halifax 421-7390

Other Services

Organization:

Contact Name:

Address:

Phone:

Email:

Website:

Notes:

Organization:

Contact Name:

Address:

Phone:

Email:

Website:

Notes:

Organization:

Contact Name:

Address:

Phone:

Email:

Website:

Notes: